

Williston Session – Written Feedback

1. In what ways do you find information about programs and services available to you and your child?

- Social Services (3)
- Through our social worker
- Physicians
- Other families – asking everyone and anyone
- OT
- I find my privacy constantly being invaded by questionnaires. Programs are available, but the issue of what it covers and what a parent's obligation is very large. Often to be told we don't qualify.
- Rely on the Doctor
- Through Opportunity Foundation
- Special needs teacher at school
- PATH office
- Flyers received at my school where I work
- Williams County Social Services
- Pamphlets in clinics
- Oral Johnson (2)
- Flyers, teachers, school, doctors, friends

2. Who is the service provider who primarily coordinates care for your child? (by title or profession)

- Dr. A Wilder
- Social Worker
- Licensed Social Worker
- Ileew Limbo
- Mother
- Opportunity Foundation
- Williston City Social Services
- School
- Pediatrician
- Jared Cvarchara – Case worker
- Jeni McCann – Ward County
- Theresa Triebull – Path Social Worker
- Dr. Code
- Dr. Ramage
- Oral Johnson – Social Services in Williston
- Cleft Palate Team in Minot (yearly)
- NW Infant Human Development Services
- Linda Hill

3. What other health care professionals or service providers assist in organizing or coordinating care for your child?

- Dr. Mills
- Dr. Staton
- Northwest Human Services Center
- Trinity Mental Health
- Family Therapists
- Psychologist
- CAPH Program
- School counselors
- Some respite care
- Barb Olson
- Clyde Vinger
- Sonia Owan – professional coordinator of Opportunity foundation
- Mavis Salla – family support services
- Dr. Duchock – play therapist from Dickinson
- Dr. Kleman
- Dr. Joshi
- Cleft lip/palate clinic in Minot
- OT
- PT
- Speech
- Dr. Souis
- Dr. Haasheer
- Dr. Reiner – orthodontist
- Physicians TCC – Western Dakota
- Mayo clinic

4. What do you like about the way your child's care is coordinated?

- Everyone seems concerned about our child's wellbeing.
- It's not coordinated well between organizations.
- Duplication of paperwork, no teamwork
- Mom has to coordinate and be on my toes all the time
- Someone will find someone to watch my child if I can't
- The Doctor's are always available when we need them by phone or in person.
We're always given choice.
- We as foster parents are allowed to include our feelings and desires, with regards to the programs that are put together for his care.
- OT and PT are on the ball to send and suggest what could be done
- I like that some services are available and the providers are willing

5. On a scale of one to five, with one being poor and five being excellent, how well do you feel your child's health care needs are being met overall?

5 (3)

3

1

3 ½ to 4

4

1 ½

6. What methods are currently in place to help assure quality care for your child?

-The county allows us to contact our child by telephone and tech-wired visits.

We are in constant touch with the staff that is caring for her.

-Mom being demanding in addition to educating professionals to think "outside the box"

-Respite care (2)

-LD Resource Room in school

-Family Support Services

-Play Therapy

-ED Resource Room at school

-Ward County Social Services

-PATH

-Cleft Palate Clinics – they are wonderful!

7. Have you gone out of state to obtain specialized services for your child? If so, where did you go and for what reasons?

-No (2)

-We took our child to the U of M for studies and MRI's

-Yes – Philadelphia, Pennsylvania. The program that works best for my two special kids is based in Philadelphia.

-Rochester, Mayo Clinic

-Specialists in Medical field

8. In what ways have you or your child received support or services from the Department of Human Services, Children's Special Health Services unit?

-Suggested a residence she could go to to be further watched

-Respite. Also interference due to lack of knowledge of autism

-I am on the parent advisory board for CSHS

-Early Childhood Screening

-Partnership Program

-Respite Care

-No

9. What types of financial assistance are you aware of that are available to support the special health care needs of your child?

- Our insurance, but it is limited to 2 months. We had to sign our child over to the county, so now we are liable for child support to the county.**
- Medicaid (5)**
- Private Insurance**
- Medical Assistance**
- We also applied for SS and were denied**

10. Have you ever been denied health care services because of financial barriers?

- No (7)**
- Yes, because there are some specialists in ND**
- No duplicate care will be covered out of state**

11. What one recommendation do you have for improving the care provided for your child and family?

- Having someone coordinating all the services for my child so she gets all the services she can get that she qualifies for. Also, make the services easier to obtain.**
- Need a central information point so information about our child can be shared with other agencies that deal with our child.**
- Coordination of information about my children and services available.**
 - Counselor who knows and can advocate and find ways to make all services available**
- Listen to the parent he/she knows their child best**
- More financial services for traveling to and from Doctors**
- Referral Resource Center where we can search out assistance**
- I would like to see Doctors communicate with me more**
- Knowledge of programs**
- Sharing of information among Doctors, parents and specialists**
- A list of services and providers for those services**
- Special Care Doctors come to Williston so parents are not traveling these many miles – this is very hard on the children and families**
- A person I could talk to about my child's ACC (Agenisis of the Corpus Colussium) and help me get the most care, chemically nutritionally, physically and emotionally that he will need starting now and ongoing.**